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Social trends such as the ageing population, the increasing numbers of people dealing with chronic conditions, the rising costs of care and budget cuts have led to a growing awareness of the need to improve care for older people. Policymakers realize that they need to restructure the health care system in such a way that it is adjusted to the requirements of our modern time and develop an alternate paradigm to underlie this restructuring. One of the major issues surrounding this restructuring is how to care for older people at home so that it optimizes their sense of mastery.

This chapter provides an English summary of the results of the study. The strengthening process whereby older people gain mastery over their situation and environment will be explored in this thesis from 1) the perspective of older care recipients themselves; 2) the perspective of their health and social care professionals and 3) from an organisational viewpoint.

General introduction (chapter 1)

In the first chapter, the consequences of an ageing society are discussed for the organisation of the health care system in the Netherlands. Subsequently, the empowerment paradigm is examined as a promising paradigm based on the social trends affecting the health care sector. Within the empowerment paradigm (directions for) solutions and strategies can be sought to face the challenges the care for older people is currently confronted with. Lastly, the aim, the research question and design of the study described in this thesis are presented.

With the ageing of Western societies and other above mentioned social trends, the awareness arises that measures must be taken to restructure the health care sector in such a way that it meets the requirements of our modern time and remains affordable and accessible for everybody. Important attempts that have been described in order to achieve this restructuring and modernization in the health care sector in Western countries are deinstitutionalisation, the shift from supply-driven care to demand oriented care and the focus of social conclusion and active citizenship of “vulnerable” citizens like older people.
These deployed developments in the care sector have an impact on diverse stakeholders involved in the care for older people. Older people and their informal carers for example, are expected to contribute more to shaping the necessary care and support. Professionals are expected to provide more care in the home environment of older people instead of in residential homes which requires competencies for professionals like being inquiringly, active, enterprising and reflective. Health and care organisations are expected to cooperate in networks of interdisciplinary care services in order to improve the integration and coordination of their care practice. Lastly, policy measures and legislation have to be developed that are in line with the shifts in the care sector as described earlier.

Parallel to the recognition of the need to modernise the care system the empowerment paradigm, came over from the United States of America to Europe. Since then, it is reasoned that the empowerment paradigm might provide a language for persons across disciplines and socioeconomic status and is often embraced as a promising paradigm based on social trends affecting the health care sector. The ultimate aim of empowerment is social inclusion and full citizenship for everybody, but with special attention to marginalized groups.

In this thesis empowerment is defined as “a strengthening process whereby individuals, organisations and communities gain mastery over their own situation and their environment through the process of gaining control, sharpening the critical awareness and stimulating participation (Van Regenmortel, 2002). A core aspect in this process is the stimulation of an individuals’ sense of mastery.

In this chapter we explored how the empowerment paradigm is regarded in the Netherland as a way of confronting and finding solutions for the challenges in Western countries where the health care sector is confronted with.

Aim of the study described in this thesis is to gain insight in the strengthening process whereby older people maintain or develop mastery over situation and environment.
This objective of this study resulted in the following research question:

How do older people manage to maintain or develop mastery over their situation and environment despite growing dependence and vulnerability and how can health and social care professionals best support this strengthening process?

In order to answer this research question we have developed a research project around a multi-disciplinary community based geriatric team in a medium sized city in the Netherlands. It concerned a qualitative and inductive research design in a natural setting also referred to as “a Naturalistic Inquiry” (Lincoln & Guba, 1985). Characteristic of naturalistic inquiry research designs is that “the research takes place in real world settings and the researcher does not attempt to manipulate the phenomenon of interest” (Patton, 2002: 39). In the selection of the multi-disciplinary community based geriatric team for this research, two important arguments where decisive. Firstly, the team worked with the same theoretical vision (empowerment) as this research departs from. Secondly, the multi-disciplinary team can be regarded as an “innovative practice” with a high “learning potential”. In the Netherlands much is written about the importance of a strong and integrated primary care. The selected multi-disciplinary community based geriatric team is one of the few teams that has been functioning for a long period of time and with satisfaction of those involved. As a result the involved professionals are equipped with a large amount of “tacit knowledge” about their care practice.

This thesis starts with a study among older people in need of long-term community care. With the aid of the concept of resilience we examined what kind of sources of strength older people themselves define as helpful in their way to deal with the age-related losses they are confronted with in their day-to-day lives. Then, we carried out a case-study in which we presented the stories of two older women. Aim of this case-study was to explore how these women mobilize various sources of strength in conjunction with one another. Thirdly, we thoroughly studied a care situation that was characterized by tensions between professionals and care recipient. Aim of this case-study was to identify mechanisms that might explain the origination of these tensions. Furthermore, paradoxes are studied
professionals in the community care for older people are confronted with in their day-to-day work. Lastly, the process of providing integrated care by means of a multi-disciplinary community based geriatric team is evaluated from the perspective of involved professionals.

Identifying sources of strength from the perspective of older people living at home (chapter 2)

Chapter 2 explores the mediating sources of strength giving rise to resilience among older people living at home who receive long-term care from the perspective of older people themselves. We performed twenty-nine in-depth interviews with older people in their own home. The interviews were analyzed with the theoretical knowledge about resilience in mind. Resilience is thereby defined as “patterns or processes of positive adaptation and development in the context of significant threats to an individual’s life or function” (e.g. Masten & Wright, 2009). The research findings show that the main sources of strength identified among older people constituted on three domains of analysis; the individual, the interactional, and the contextual domain. The individual domain refers to the qualities within older people and comprises of three sub-domains, namely beliefs about one’s competence, efforts to exert and the capacity to analyse and understand one’s situation. Within these subdomains a variety of sources of strengths were found like pride about one’s personality, acceptance and openness about one’s vulnerability, the anticipation on future losses, mastery by practicing skills, the acceptance of help and support, having a balanced vision on life, not adapting the role of a victim and carpe-diem. The interactional domain is defined as the way older people interact with others to maintain mastery over their situation and environment. Sources of strength on this domain were empowering (in)formal relationships and the power of giving. Lastly, the contextual domain refers to the broader political-societal level and includes sources of strength like the accessibility of care, the availability of material resources and social policy. The three domains were found to be inherently linked to each other. In this chapter, we presented this inter-connectedness as gearwheels that need to interact favourably in order to create an optimal climate for development (i.e.
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resilience) to occur. The results can be used for the development of positive, proactive interventions aimed at helping older people build on the positive aspects of their lives. Since the results in this chapter show that resilience is situated on three interrelated levels of analysis, recommendations can be made for older people themselves, their families, their caregivers as well as policymakers.

Older people are recommended to discuss their wishes, expectations and life goals in an early stage with their family and professionals. They need to realize that accepting help and support and using medical devices like a rolling walker or a personal alarm may allow them to remain in their own home for a longer period of time.

Family and professionals must recognize that accepting help and support is not an easy task for older people. For older people it is important that their family and professionals allow them space and support them in this process. For policymakers the results of this study can give insights that make them aware of the importance of contextual factors in the extent in which resilience can flourish. Their policy should be aimed at creating space for older people so that they are enabled to maintain mastery over their situation and environment, for example by financing “tailored care”. Also, attention should be paid to the removal of contextual factors that might hinder resilience processes.

Narratives about revealing resilience (chapter 3)

In chapter 3 we are building on the insights from chapter 2 and describe how older people mobilize diverse sources of strengths in conjunction with each other in order to maintain or develop a sense of mastery over their situation and environment. The study discussed in this chapter entails two personal narratives of two older women living at home and their experiences in dealing with significant threats to their life and function. We wanted to gain insight in what was going on in their lives, how they looked upon their lives and how they dealt with the losses that accompanied their old age. An important finding from chapter two is that the environment and context plays an important role in the way older people confront their age related losses. In chapter 3 we therefore specifically focused on how older
people interact and cooperate with others to maintain or develop a certain sense of mastery. Similar to chapter 2 we used the concept of resilience to obtain in-depth insights in the sources of strength that older people mobilize to be able lead a qualitative good life, despite their experiences with loss. The narratives of the women show that, what on the surface appears to be a similar burden to a life or function, turned out to be interpreted and responded to in a different way. Both women framed their narrative in a different way. In both stories the burden the women had to carry as well as their capacity to deal with that burden was discussed. However, the extent as well as the intensity with which this was done differed: whereas in the narrative of the one woman within the balance of burden and capacity was on the burden she faced, the emphasis and intensity in the narrative of the other woman was on her capacity to deal with losses accompanying old age. Based on the analysis of the narratives we conclude that gaining mastery over one’s life is an interactional process in which both older people as well as significant others have a role to play. Important sources of strength that can positively influence this process are a positive perception of one’s situation, openness about one’s vulnerability, the responsiveness to help and support from others and the ability to give something to others besides receiving care from others.

Based on “the motivational theory of life span development” (Heckhausen et al., 2010) the research findings show that it can be worthwhile for older people to disengage from life goals that are no longer attainable for them and select goals that are more realistic to achieve. For example by adjusting expectations, values and attributions.

Moreover, the narratives show the importance of reciprocity in a care relationship. In a reciprocal relation both family, professionals and care recipients are both subject and actor in an equal relationship. In order to promote older people’s sense of mastery, significant others like family and professionals need to approach them in a positive way. This can be achieved by being aware of the way support is offered, by believing in their potential and strength, by seeing older people as resilient persons with their own identity, values and past and by allowing reciprocity in the care relationship. When these conditions are fulfilled, it becomes possible to enter into a constructive dialogue and recommendations can be developed - in terms of treatment - that are consistent with older persons’ values and
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expectations without giving them the feeling that their sense of mastery is deteriorating due to the fact that they accepted the help and support from others.

Risk prevention or health promotion? (chapter 4)

Chapter 4 describes a care relationship that, besides contentment, is characterised by tension and ambiguity. This care recipient was not willing to accept some forms of help, despite the individual package of support that was specifically designed by her professionals for her situation. It concerned a 79-year-old, illiterate woman who lived alone. She had the explicit wish to remain living independently and to take care of herself. However, since the death of her husband, the professionals worry about her health condition as well as her safety.

Many older people in western countries express a desire to live independently and stay in control of their lives as long as possible in spite of afflictions that may accompany old age. In some care situations, tensions may arise between professionals and care recipients whose views on risk prevention and health promotion may differ. In this chapter we use the theoretical framework “salutogenese” from the Israeli sociologist Aaron Antonovsky to explain the pathways that may explain the origin of these tensions. His approach essentially grew out of his concern that health care often adopts a pathogenic/deficit driven approach that over relies on risk, rather than putting the emphasis on protective mechanisms. This, according to Antonovsky, were two different ways of looking upon health.

Antonovsky promoted a Sense of Coherence as a path to better health. According to him, this Sense of Coherence consists of three components: the way people endow meaning to the stressful or demanding circumstances they encounter (comprehensibility); their perceived feelings of control (manageability) and their motivation to comprehend and manage events (meaningfulness). According to Antonovsky, the third element is the most important for explaining the forces that lead to people to grow healthily. We illustrate the origination of tensions and ambiguities in a care relation with a case-study of an older woman living in the community in relation to her health and social care professionals. We subsequently analysed this case
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critically and systematically by means of the theoretical insights of Antonovsky.
The case-study reveals that, although the professionals had good intentions, were engaged in her situation and offered tailored care, the responsiveness to care offered to this care recipient could not be taken for granted. While the care recipient focused on her strengths, the professionals were focussing on risk prevention. This difference in pathways health promotion can create misunderstanding, conflict and tension in the care process. The care professionals assume that the care recipient does not seem to be sufficiently aware of the risks that are an inherent part of her life. They believe she should be aware of these risks and take them into account. At the same time the care recipient is not focused on these risks and doubts whether the professionals are sincere in their intentions. Moreover she feels that the professionals do not really understand her qualities, skills, motivations and aspirations.

We conclude that attention must be paid to the way older people endow meaning to the circumstances they encounter as well as to their motivation to comprehend and manage events. This can be achieved by bringing (the) differences in perspectives of both professionals and older people closer together. The three components as described by Antonovsky (comprehensibility, manageability and meaningfulness) are useful tools in this context. In order to improve the quality of life of older people, it is necessary that both professionals and care recipients have an open mind towards each other and try to understand each other’s perspectives. Only then they can engage in an open dialogue with each other, taking the life narrative of care recipients into account.

Paradoxes in the care practice of older people living at home (chapter 5)

In chapter 5 a study is presented aiming to gain insight into the paradoxical situations professionals are confronted with in the care of older people living at home. Moreover, the way professionals subsequently responded to and intervened in such paradoxical situations was explored.
An important task for professionals during the care process is to support older people in their way to deal with their declining health and other afflictions that may accompany old age. During this process older people are confronted with difficult choices and considerations. Professionals are often closely and explicitly confronted with the problems of their older care recipients. Until now relatively little is known about how professionals give substance to his supportive task in their day-to-day work.

We analysed the cases that were discussed within the multi-disciplinary community based geriatric team by means of the paradoxical situations at hand. The cases were referred to as paradoxical issues when they met the following criteria: 1) two or more (apparently opposed) values were at stake; 2) two or more different choices for intervention strategies were possible and 3) professionals experienced some “professional space” to make their own choice between the various possible intervention strategies. As we followed the professionals for 1.5 years we were able to gain insight into how professionals responded to these situations over time.

The analysis of the data demonstrate that providing care to older people is a dynamic process in which the intervention strategies of the professionals mainly focus on bringing back in balance the various paradoxes as experienced by professionals. This is illustrated in this chapter by presenting three paradoxes that emerged within the data: respecting autonomy versus preserving safety; the care needs of the care recipients versus the capacity of their informal carers to cope; and holding a formal orientation versus a tailored orientation on tasks.

The intervention deployed by the professionals were all aimed at addressing paradoxes by bringing the involved values back in balance. Even though the values in each case seemed at first conflicting, eventually it turned out that the conflicting values were reconcilable partly due to the creativity of the involved professionals. Moreover, the intervention strategies turned out to differ per case (tailored care) and to evolve during the care process (in line with the dynamic course of the care needs of the care recipients). Lastly, the input (or used professional power) of the professionals was found to vary between “being present” at a relative distance and “making decisions for others”. Being a safety net and keeping an eye on the situation turned out to be an important and effective “act of intervention” used by professionals to support older people in their home environment. In a number of situations
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this “being present” was the starting point from which other interventions were employed like a temporary admission to crisis bed, increasing the amount of (in)formal care or the application of the relocation to a residential setting.

We conclude that providing care in the home environment of older people requires a continuous anticipation of (un)expected evolutions in situations of their care recipients. Continuous attention should be paid to balancing the different values that are important in the lives of older people. For professionals this implies that they do not rely on protocols and organisational rules alone, but that they also take their conscience, professional knowledge into account in order to optimally respond to these moral and ethical issues. To optimally support older people and address the balance within the paradoxes, professionals need “professional discretion”. They must be supported to systematically reflect on and legitimize their intervention strategies. The multi-disciplinary community based geriatric team appears to be a suitable way to realize this.

Experiences with the provision of integrated care (chapter 6)

The aim of chapter 6 was to gain insight into the experiences and perspectives of professionals with the implementation of multi-disciplinary cooperation to improve the integration of care and support for older people living at home.

The last decades, policymakers acknowledge the need to restructure the health care system in such a way that it meets the requirements of our modern time. This applies in particular to the care and support close to older people. One of the key points in policy is to strengthen the local cooperation between various professionals and health and social care organisations. However, there are signs that integrated care is hard to realize in practice. Hindrances that are mentioned include cultural cleavages between professionals, interface problems between organisations and organisations, organisational and procedural rules and regulations prevailing in the sector, the supply-driven design of the system and financial and legislative problems. In order to measure the effectiveness of policy measures like the integration of primary care, it is important to gain insight into the
perspectives of those people who implement it. Until now, relatively little empirical research has been published on the perspectives of professionals in integrated care for older people living at home. Therefore, we conducted a research project in which we observed a multidisciplinary community based geriatric team, conducted in-depth interviews with professionals and organised two focus groups with involved professionals.

The results show that professionals distinguish five themes concerning integrated care: 1) the quality of care practice and care relations; 2) professional development; 3) the functioning of the team; 4) network relations between organisations; and 5) contextual conditions. The results fit within the “Nomological framework of Organisational Empowerment (OE)” as described by Peterson & Zimmerman (2004). Their model turned out to be helpful in gaining a deeper insight into the role of organisational features in achieving integrated care. Furthermore this model can be used to help identify possible strengths and weaknesses of the chosen organisational structure. Peterson & Zimmerman (2004) investigated diverse processes and outcomes on the organisational level of analysis and subsequently distinguish three components that may be critical for the performance of an organisation and thus for the extent to which “organisational empowerment” might occur: the intra, inter and extra-organisational components of organisational empowerment. The intra-organisational component of their framework includes characteristics that represent the internal structure and functioning of organisations. The inter-organisational component includes the linkages between organisations. The extra-organisational component refers to actions taken by organisations to influence the larger environment of which they are part.

In the intra-organisational domain, trust between the involved professionals and involvement of the perspective of the care recipient in the care process are crucial. In the inter-organisational domain, the promotion of integrated care as an essential part of the work of professionals deserves attention. In the extra-organisational domain policymakers should listen to the suggestions for areas of improvement of professionals and let them have a say in contextual factors that influence the care process.

The chapter concludes with the statement that the provision of integrated care requires an active contribution from all stakeholders involved: i.e. the
involved care recipients, (in)formal carers, the multi-disciplinary community based geriatric team, the participating organisations and policymakers.

Summary and discussion (chapter 7)

This concluding chapter provides a summary of the main results and the implications of the research findings of the study described in this thesis, followed by a reflection on the research methods used. Lastly, recommendations are made for further research as well as for practice.

A new insight that stems from this thesis involves the role of resilience processes and mechanisms on the extent to which older people experience a sense of mastery over their situation and environment. We found that, in addition to general sources of strength, they also possess sources of strength that are specifically associated with old age. Furthermore, we notice that resilience processes are often revealed in relation with significant others. Resilience, must therefore be regarded as a dynamic, contextual process that takes place on the individual, the interactional as well as the contextual domain of analysis.

A second insight this thesis provides is the importance of the expressive function with which professionals support older people. We conclude that having insight in “the Sense of Coherence” of older people can be an important key to the provision of care and support that is in line with the values of older people. With the aid of the theoretical insights of Antonovsky we developed ideas what it means to look upon preventive measures with a salutogenic point of view alongside of the reduction of risk factors and health threats.

Thirdly, this research provides insights about paradoxes that appear to play an important role in the care and support of older people living at home. The challenge for professionals turn out to address these paradoxes in such a way that the delicate balance between the apparently contradictory values at stake is restored again. Examples of these paradoxes found in the community care of older people were respecting autonomy versus preserving safety, the needs of the care recipients versus the capacity of their informal carers to cope, and holding a formal orientation versus a tailored orientation on tasks.
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Fourthly, we found that providing integrated care to older people living at home by means of a multi-disciplinary community based geriatric team is a promising way to support older people in their strengthening process whereby older people maintain or develop mastery over their situation and environment. Yet, in organising such team attention must be paid to intra, inter and extra-organisational factors. Mutual trust, clear working routines during the team meetings and support from the management of involved organisations can contribute to achieve this. A point for improvement thereby is the influence professionals can exert based on their experience on government policy as well as the care policy for individuals. We see a future role for municipalities and recommend them to develop their local policy in close cooperation with professionals and care recipients.

In this final chapter we also reflect on the research methods used. The most important strengths of our research design were the prolonged engagement in the multi-disciplinary community based geriatric team and the inclusion of the perspectives of various stakeholders involved in the elderly care. Important points of attention of the research design were the generalisation of the research design, the fact that we interviewed the older care recipients only once and the fact that we did not include the perspective of informal carers in our research design.

Finally, recommendations for practice have been done.

The point of departure of this thesis is that in order to modernise the elderly care the strengthening process whereby older people maintain or develop a sense of mastery should be a central aspect.

A prerequisite to achieve this is the awareness that in order to foster mastery one cannot focus on one type of intervention alone, but measures and interventions need to be taken on the micro, meso, as well as the macro level. The mere allocation of responsibilities to older people and their informal carers to let older people live in their own homes for as long as possible is inadequate. Ideally, allowing older people to experience an optimal sense of mastery requires an active contribution from all stakeholders involved in the care process. Older people need to be open to the care and support offered by significant others. (In)formal carers need to provide care that is in line with the resilience processes mobilized by older persons. Local organisations need to work closely together, based on mutual trust and clear and jointly supported goals. For municipalities and the
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federal government it is important that they create preconditions for professionals to support older people optimally in their strive to maintain mastery and develop policy that is based on what Chapin (1995) defines as “negotiated truth”. This concerns policy that is not only based on theoretical knowledge, but also on experiential knowledge of older people and professional or tacit knowledge of health and social care professionals. Mastery has become a frequently used concept that is interpreted differently by different persons. Therefore mastery is at risk to become a meaningless concept. On the one hand it refers to autonomy in the sense of being independent and on the other hand to gaining control over the care people receive and over one’s own life. Our research findings show that fostering mastery is not only a matter of gaining control, but is especially associated with experiencing meaning in life and with living a life that is in line with the values of older people. When an older person does not experience meaning and “a Sense of Coherence” in life anymore fostering mastery has become useless. Professionals should therefore pay more attention to support older people in finding meaning in their lives.

Furthermore, in order to support the before mentioned strengthening process of older people, a strength-based view on older people aimed at connecting people by all stakeholders is necessary. This strength based and appreciative view has consequences for how we should look at preventive measures.

On her website the European Union states that “No matter how old we are, we can still play our part in society and enjoy a better quality of life. The challenge is to make the most of the enormous potential that we harbour, even at a more advanced age”. Achieving this is responsibility of all stakeholders involved like older people themselves, their social network, professionals, health and social care organisations, universities of applied science, policymakers and scientists.
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